

PCAST Report Workgroup
Draft Transcript
March 30, 2011

Presentation

Judy Sparrow – Office of the National Coordinator – Executive Director

Good afternoon, everybody, and welcome to the HIT Policy Committee's PCAST Workgroup. This is a Federal Advisory Committee, so there will be opportunity at the end of the call for the public to make comment, and just a reminder for workgroup members to please identify yourselves when speaking. We are making a transcription.

A quick roll call: Paul Eggerman?

Paul Eggerman – Software Entrepreneur

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

William Stead?

William Stead – Vanderbilt – Chief Strategy and Information Officer

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Steve Ondra? John Halamka? Dixie Baker?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I'm here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Wes Rishel?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Stan Huff? Leslie Harris?

Leslie Harris – Center for Democracy & Technology – President & CEO

I'm here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Bob Kahn? Gary Marchionini?

Gary Marchionini – University of North Carolina – Dean & Professor

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Richard Platt?

Richard Platt – Harvard Medical School – Professor & Chair

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Carl Gunter?

Carl Gunter – University of Illinois – Professor

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Hunt Blair?

Hunt Blair – OVHA – Deputy Director

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Tim Elwell?

Tim Elwell – Misys Open Source Solutions – Vice President

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Steve Stack? Mark Rothstein?

Mark Rothstein – University of Louisville – Chair of Law and Medicine

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Eileen Twiggs?

Eileen Twiggs – Planned Parenthood Federation of America – Director

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Jonathan Perlin?

W

Not available yet, but will be joining shortly.

Judy Sparrow – Office of the National Coordinator – Executive Director

Okay, thank you. Doug Fridsma?

Doug Fridsma – ONC – Acting Director, Office of Standards & Interoperability

Here.

Judy Sparrow – Office of the National Coordinator – Executive Director

Did I leave anyone off?

Jodi Daniel – ONC – Director Office of Policy & Research

Jodi Daniel.

Judy Sparrow – Office of the National Coordinator – Executive Director

With that, I'll turn it over to Paul Egberman and William Stead.

Paul Egberman – Software Entrepreneur

Thank you very much, Judy. I want to say good afternoon or good morning, whichever is correct wherever you are. Welcome to our workgroup conference call. This is a conference call of the PCAST Workgroup. We were organized after PCAST (the President's Council of Advisors on Science and Technology) issued a report in early December 2010 that was called "Health Information Technology, the

Path Forward.” That report called for a number of items, but it asked that ONC (the Office of the National Coordinator) act boldly and aggressively. One of their bold and aggressive steps was to create this workgroup to help ONC decide what are the different impacts the report might have on them. As far as acting aggressively, they gave us a very aggressive schedule, so we’ve been meeting for a few months and now we’re at a stage where hopefully we are reviewing, I’d like to say final, but a near final draft of a report that we will be presenting on April 13th to the HIT Policy Committee.

Our agenda today has three main topics. One topic is review of what’s called deployment models. This is the section of the report that we really haven’t done a thorough review yet within the workgroup, so I want to make sure that there’s some consensus about what it says in the report. Then we have two open areas for discussion. One is simply to allow workgroup members to raise questions or topics, or any areas of the report that they have questions about or they disagree with or anything like that that they want to raise. The last topic that we want to do is also to discuss our concluding paragraph, basically a concluding paragraph the way I look at it is a chance for us to emphasize one or two or maybe three things that we think are really important from our report and bring that forward to whoever will be reading the report. Then we will also have of course public comment. I do want to make sure that I welcome any members of the public who are listening to our call, I want to tell you that, as you will see when we go through the report, your comments, the public comments are critical to our reports and our deliberations.

That’s a quick review of the agenda. I don’t know if I left anything out. Bill Stead, do you have any comments? I think, Bill, if I remember, is at an airport, and may have difficulty with his mute button, but I’ll assume he doesn’t have any comments.

Unless we have some questions, I’m going to get started on the review of the deployment models. Before I do that, let me make sure. This is a list of the workgroup members, and again I want to thank everybody for their hard work on this workgroup, and also here is the workgroup charge written out. The charge, as you see, has four components. The first one is, as I said, is assist ONC in synthesizing and analyzing the public comments. The next ones involve the implications of the report and its recommendations to ONC on current strategies and then the feasibility and impact on ONC’s programs, and finally, how the recommendations could be integrated into ONC’s strategic framework. So that’s our charge. As you can see by the list of meeting dates, this is our last scheduled meeting. We have been meeting very diligently since January 7th.

Here is the information about the deployment models. What you see on your screen at first glance may look a little nonsensical, this top-down, bottom-up, and middle-out. These are actually references to terminology. I think it’s in a book that was published by somebody at the Gartner Group. Have I got that right, Wes, is that where the terminology came from? But I believe that’s what the basic concept is. What I want to do is I’m going to quickly take you through some slides of what this means, top-down, bottom-up, and middle-out, so I’m going to go through it very rapidly. Then I’m going to stop at the middle-out piece and we can try to discuss what it says in the report about this and any observations that people have.

The concept of these different approaches, the first one, the concept of top-down I listed six or seven activities of ONC. But the concept of the top-down model to deployment would be that ONC would be very directive, from a top-down basis ONC would make a lot of decisions. Besides ... the policy questions, ONC would make technical decisions, it would define the components of the UEL, the syntax, it would establish the DS, it would fund the governance. It would basically be very assertive and would simply implement the entire PCAST architecture. So that’s the whole concept of how a top-down model works.

The second model is the bottom-up model, and the concept of that is almost the direct opposite, so that what you do in a bottom-up model is you have an environment where you have multiple different organizations doing things, perhaps independently, so this would be vendors or private projects independently trying to implement—I’m sorry, is somebody saying something? Anyway, the concept of bottom-up is people try to independently implement the PCAST model. When I first wrote this up in the early drafts of the document what was interesting was I got feedback from people and they would say

things like “too timid,” “too slow,” “this doesn’t sound right,” and I actually revisited this though in the most recent draft for two reasons.

One that was very interesting to me is I had a communication from a large vendor who indicated that they were considering creating their own concept of a DEAS and starting to implement ahead of where the government is. I looked at that and I said that’s actually encouraging, because we could learn some stuff from that. They asked an interesting question when they told me that, they said what are the standards for the DEAS, because they were there to do it, they want to do it according to the standards. That was actually an interesting question.

The other thing that caused me to revisit this a little bit was actually some feedback from Tim Elwell, who made some suggestions that actions that could be taken, which originally I couldn’t tell you what the actions would be related to this model, but to make some suggestions that set me on a path. But the idea is you could get situations, like SBIR gives grants to really small businesses to help them do things that are helpful, you’ve got VA and also, I didn’t list them here, but DoD and Indian Health systems, IHS, maybe when they do contracting they can put contracting requirements out that would cause vendors to create certain systems. You could ... possibly open source implementations could be encouraged, and of course, you still have policy questions that are resolved. So that’s the bottom-up concept.

Then you have this other concept that’s called middle-out and, again, as I said, Wes did a great blog on this, but the concept about middle-out is that the role of ONC or the government would be really around developing standards. Part of the concept, and people need to correct me if I’m saying this wrong, but one way to look at the Internet would be to say well, what is the Internet? So you could look at the Internet and say, well, it’s just a group of standards. There are standards for HTTP. There are standards for secure Caucus. In fact, sometimes the standards don’t necessarily make sense. But it’s a group of standards and people took those standards and they did business solutions based on those standards.

So the concept of the middle-out is you focus on creating the standards, and the comment that I tried to write in the report was to say that you’ve got these three models but it’s not like we’re saying ONC has to choose one or the other. Of the three models, certainly the middle-out model is probably closest to what I would call ONC’s comfort zone, because it’s closest to what ONC is currently doing, but you can picture an environment where you do portions of each. So in the middle-out model you would establish standards for a lot of things. You see here are the standards around vocabularies and syntax and the kinds of things that ONC does, but what it didn’t list in this list is anything about the DEAS, which is the record locator service, which is, I think, the trickiest part of the architecture to figure out.

So you could picture a situation where you’re establishing standards but you use the bottom-up approach to have two or three or four different competing versions of the DEAS out there to try to figure out what’s going to work and what’s not going to work. Maybe at some point there’s a decision to say, well, there’s going to be a top-down approach and ONC chooses one, and so then that would be one view of how you would actually inter-mix these models.

Robert Kahn – Corporation for National Research Initiatives – President & CEO

Can I just make one comment on this?

Paul Egerman – Software Entrepreneur

I’d love to hear your comments on this.

Robert Kahn – Corporation for National Research Initiatives – President & CEO

I actually think it’s the simplest part of the architecture rather than the most complex if one has agreement on the use of identifiers within the architecture. I think that’s been the stickiest point because for a lot of the concerns people have expressed with all the bad identifiers for individuals, you have identifiers for the records. You have identifiers for places where things are located and the like, and if you could converge on some way of dealing with identifiers, maybe you mask the identifier for the actual patients, then it seems to me it becomes almost the simplest thing. You’ve got some existing choices out there and you could, I suppose, go back to the drawing board and start from scratch.

I just don't think it's the most complicated part. I think the more complicated thing is going to be to get people to get their head wrapped around the notion that you can have meta-level descriptions of interfaces and records without having to actually define the contents of them up front. Then you can have certain categories of usage, for example, where you say, well, okay if we're using this category of usage here's what it masks into, and they can change those over time. So, for example, if you went into the Appendix B of the draft that you submitted, where under technical architecture components it says "Use of an extensible language" and you give XML as an example. When I raised that notion of metadata interfaces the last time, I was thinking of something that would let you say within this extensibility that we're using XML as an example, not that XML was the example of the extensible language itself. So it's a higher-level description of these things, which I would call meta-level descriptions. I think with the right architectural point of view some of those things become easy but they may be politically ... if you have troubles with people agreeing to use UNIX identifiers.

Paul Egerman – Software Entrepreneur

That's a valuable comment. What did you think about this discussion, like middle-out and standards?

Robert Kahn – Corporation for National Research Initiatives – President & CEO

Well, I had a little bit of the same problem there because for me the thing we did with the Internet that was I think necessary at that time was we actually defined the standards in gory detail. So if you're sending e-mail from place to place, there are standards for e-mail. If you were passing stuff from one machine to another there were defined standards, where the bits were, what the formats were and so forth. Today we're at a point where you can say this is the way communications will take place between the machines and you can say by the use of identifiers what the actions are, what they map into, what the targets are, what they map into. So one defined interface ought to live through generations and generations of standards bodies that decide to deal with those things in different ways.

I actually like the middle-out approach the best, quite frankly, because you're going to have some people try and start out with projects where they literally define top-down. You're going to have other people where they just started building things, which I guess would be the bottom-up, and you're going to have to work in the middle and work with all the parties doing whatever they're doing. I think it just needs to be described in a sufficiently high meta-level way that it allows for whatever people are doing at each level, below or above, to be mapped in appropriately.

Paul Egerman – Software Entrepreneur

Again, these are actions for ONC, for the government. The idea is working in this middle-out level the government would hopefully establish the right standards that would facilitate and encourage all these other activities you just mentioned.

Robert Kahn – Corporation for National Research Initiatives – President & CEO

I think they can ... generic meta-level ways of interfacing to say if you're going to communicate, we don't care exactly what standards you use or how you represent different things. But if you're going to convey them, here's the method of packaging them to get them to the other side, and it's all based on identifiers so that people know how to de-reference things. But what you're talking about can be the result of as many groups that want to get together and define their own way of thinking about things. Because if you picked a set of standards today you want to pick maybe a slightly augmented set of standards or a different set of standards at some point in the future and you don't want to have to have the previous investments and implementations suddenly be invalidated just because you've changed the standards and the way they're described.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I'd like to speak next ..., but Bob, I didn't want to cut you off.

Robert Kahn – Corporation for National Research Initiatives – President & CEO

Okay, I'll be quiet.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Okay. Bob is preaching the gospel of how the Internet developed. In one area I would qualify his statement that the early work was all about where the bits go. I would say that the early work was characterized by simplicity and the ability to compose that things were done in anticipated ways and in unanticipated ways. That the experience then of different people going off and trying things different ways, getting some things working and then using that as a way to solidify a few more building blocks has turned out to be fantastically successful. Bob, do you feel that's a fair characterization of the—?

Robert Kahn – Corporation for National Research Initiatives – President & CEO

Yes, that's how the Internet grew organically, through that mechanism. But we were basically dealing originally only with connectivity, how do you make sure that this got from one place to another? We're tackling in the healthcare problem a much more—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I agree, but the point I was wanting to make is that the experience we've had in healthcare over the years tends to redefine the entire stack, with tall stacks of standards that are unnecessarily interrelated between levels of the standards. That has proven to be problematical when industry players with tremendous Internet resources came into the healthcare arena because all of the tools they wanted to bring to bear just didn't quite fit, didn't quite apply. I think that there is a sweet spot between defining too much and defining too little, that the sweet spot starts with the kind of effort that the Direct Project did, which was to gather parties that are interested in implementing and establish some consensus on how to use existing Internet standards as a base platform.

The sweet spot—and this is speculating what a group would come up with, but I think that would go out as far as MIME and a few other basic formatting standards like that. A similar set of narrowly defined standards to deal with identifiers, as Bob has identified, not meaning to be ironic, and sort of fundamental bucket structure. So that people who are getting together to agree on metadata or developing techniques to interpret existing material and apply metadata to it have a fundamental understanding of where to find the metadata and maybe some fundamental structure about the metadata or something like that. Part of that is the UEL, in other words, the UEL is not a fantastically detailed semantic model for all healthcare data. It's a bucket describer that lets people find out what they're dealing with inside the bucket. Then at that point there are many format standards that exist, there are many content standards that exist for clinical data, maybe they're right, maybe they're not. Maybe, as is the case today, the developers that are the most successful deal with those on a more or less modular basis, but with a sweet spot between no new standards and a lot of new standards we enable the most rapid innovation.

I think that by government standards the Direct Project was dirt-cheap and had two advantages. One, it had highly incented players fighting for what they believed in and it had a commitment to getting to actual operation within a very limited time frame. I think a similar type arrangement around the UEL and the fundamentals of the DEAS could be a very effective way of taking it forward.

Paul Eggerman – Software Entrepreneur

The sense I'm getting from what I'm hearing from Wes and Bob, and you guys tell me if I've got this right, is that the descriptions of the middle-out model that I've got here is wrong. What I'm really missing is this concept that it really should be a focus on what are the simple, basic fundamental standards that are needed.

Carl Gunter – University of Illinois – Professor

Before they answer that I wanted to interject something for their consideration. My understanding was the early days of the Internet received a considerable amount of government support and for many years there was no support for the Internet other than government support, and I don't hear that reflected in this discussion of just setting up standards, I mean, design of prototypes, design of networks, experiments, search projects, extensive support.

Paul Eggerman – Software Entrepreneur

Okay. So basically I'm hearing what you're saying is you've got to do more than standards. In other words, it's like this middle-out approach works, but you're going to have to do something more.

Carl Gunter – University of Illinois – Professor

Yes, the interest in the standards was partly driven by the work that was being –

Paul Eggerman – Software Entrepreneur

That's right, and I'm getting two or three concepts here. One is that the standards need to be fundamental and basic and it's like identity was called out. The second is that there's an iterative process. In other words, you develop some standards for some things and some things happen in the real world and then you realize you need some standards for something else. The third is what you're saying, Carl, is that it's not just standards. You've got to do something more. In other words, at some point you have to fund some projects. If you want to get the thing moving you can't just issue the standards and stand back.

Robert Kahn – Corporation for National Research Initiatives – President & CEO

Let me maybe flesh out some of these ideas a little bit better and just have a little sidebar discussion here on the notion of the UEL, because the way it's described in the documents basically it sounds like that's a very detailed language in some sense. Yet when I look at something like that, first of all, ... as an envelope, and I don't happen to think of it as an envelope. I think of it as a way of communicating from one place to another. To me the way that that works to the long term is if the communication is based on identifiers.

So, for example, let's say you have a way of structuring things where you say here's where you put the identifier that's the action you want to be taken. Well, for the next hundreds of years people are going to want to specify actions to be taken. It may be just deposited, it may be get something, it may be change something, whatever it is, but if you have an identifier that resolves to an executable. It could be a program that somebody wrote. It could be coming built into systems because they know what it is ahead of time, that's one thing, and another identifier that's the target of that action, or you could have a set of identifiers that are the targets of the action. If you have a description of the language in that level, that's what I call a meta-level description, because it's not specific to any particular action, it's rather a method for describing any possible action on any possible object at any time now or in the future. I don't know what other people think about when they think of UEL, but that's what I would hope it would end up—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I would say that, as described in the report, there are effectively four kinds of metadata associated with a bucket or an element, or what they called an atom, which I think they really meant was much bigger than we think of in atomic. But fundamentally they had to do with provenance, privacy, consent, fundamental structure, and I think what Bob is calling identifiers. I would argue that defining that in the abstract is necessary but insufficient to get started, that some of the identifiers for actions have to be identified. So being able to locate information, either by patient ID or associatively, would have to be an identified action and being able to deposit or update information might have to be an identified action. But that the level of that second set of definitions should be as minimal as possible for some group of people to go to an agreed upon result, that is, it should continue to be mostly undefined and therefore highly extensible.

Robert Kahn – Corporation for National Research Initiatives – President & CEO

That sounds exactly right, the way you just described that, except that the way it's written in our report, on page 17 it talks about supplying all the health data in a standardized envelope. That is so old school that I think it to me implied that this notion of what UEL is all about is at completely the wrong level.

Carl Gunter – University of Illinois – Professor

I think the term “envelope” here For example, you have the contents of the envelope like a letter sent by post, and you're going to have all kinds of things that go inside but something fairly standard to mark the outside so that the outside would be basically just a number giving you some hint as to what to make of the inside of the document. Maybe we're using the term “envelope” differently. I'm just thinking of something like a minimal header that has a number that gives you the description type of the contents.

M

But that would be metadata, and I would not view any of that as being in the genre of envelope.

Carl Gunter – University of Illinois – Professor

Okay, I think ... determine a logical—

M

Yes, what would be the right noun for a “MIME” option?

M

I would just simply say the... providing in a standardized form or in a standardized structure might be better. ... interpret the structure to figure out what the actual one is.

M

... package also.

Paul Egerman – Software Entrepreneur

This is an interesting discussion, but I want to make sure. What I’m trying to focus in on is what I said about this in the report, about this thing called the middle-out model. What I’m looking to hear is what we should do with what we wrote about in the report. In other words, should we change this to make it clear that we’re looking at a certain set of what people are calling fundamental or basic standards, should I just take the whole thing out, that maybe it’s not useful? What should we be doing about this part of the report?

Robert Kahn – Corporation for National Research Initiatives – President & CEO

Paul, you had actually asked if I would generate something in writing, and unfortunately, I was so tied up in other things this week I never got around to it. Would it still be timely if I could get something to you in the next few days?

Paul Egerman – Software Entrepreneur

Yes, that would be extremely helpful.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I have been in a similar situation. Anything can happen on the weekend. So if something could be provided by Monday, I’d be happy to do that. I’d be happy to swap notes with Bob if that would be helpful.

Paul Egerman – Software Entrepreneur

What I’ll do is I’ll talk to both of you off line, and I might try to see if we can push it a little bit earlier than Monday, but to take this up a level. The sense I have, though, is that this middle-out model is a useful part of the entire process that needs to be defined a little bit better.

Robert Kahn – Corporation for National Research Initiatives – President & CEO

Another way to think about this is that the only way you’re going to roll out a national level system is by individual groups in different places making their own decisions about what they choose to do. I’ve been through this issue with the court system when they were trying to figure out could there be a uniform thing, I’ve been through it with many different groups, and ultimately people make their own decisions. Then the question is, what kind of guidance can you give them up front so that even if they do make their own decisions you have a good fighting shot at making it all work together in some way. Rather than giving everybody a detailed implementation spec that says buy this equipment, buy that software, start your things this way, that way, at very low levels. I think you’re going to have to deal with that no matter what, probably because there are already lots of systems that are out there that people will want to factor in. I think operating from the middle is the right place to operate, but I would rewrite it somewhat to try and essentially pose the problem that you’re likely to be really dealing with.

Paul Egerman – Software Entrepreneur

That's right, because, Bob, what you just said makes sense. I was talking to a vendor who said that they were interested in creating their own DEAS but they wanted to know what are the standards. So the idea is you have these independent groups doing things, but they do need some level of guidance and as they go forward they may have very specific issues that they would like standards on.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Paul, if I could comment on that. I think vendors that have had experience in succeeding by creating impact on the Internet, that is by being a leader that people follow or knowing when to be a follower and when to be a leader, are looking not to avoid using standards, but they're not looking for a full stack definition of standards. They understand the edge of that growing concentric set of modular standards is where innovation is happening.

Paul Egerman – Software Entrepreneur

It's kind of like the police. You only want them when you want them. That's my view as a former vendor. I want the standards that I need. I don't want anything else.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

But also I think in the day with HIT vendors there was a strong tendency to say, well, if the standards aren't fully defined they're not useful. It is always the case that a fully worked out, tried by economic success and confirmed ... set of standards gets you to some immediate place sooner. But the assumption that we can specify that much at one time and make a giant leap rather than going by steps has been also proven to be invalid. The vendors are pretty well satisfied with understanding how to work at the edge there, how to work with existing standards as long as they work for their needs, and then innovate at the edges. I would go so far as to say so this initial sweet spot set would include a way of describing how information is semantically formatted, but not that it would specify any one way of formatting it as the only way that works. But at least you can discover from the bucket they think this is HL7 version 2, or they think this is a PDF text note of an EKG or an ECG analysis and so forth.

Robert Kahn – Corporation for National Research Initiatives – President & CEO

One way that you can, again, make that one level of ...direction is if every element within a particular digital object model of the world is described in, let's say, a form of type value pairs, that's an entrée into the semantics. Because the type can tell you as much semantics as you want about the elements, how to process it and the like, we don't actually deal with bytes of that form as things that standards bodies have to figure out. What we do is deal with it within the architecture, that's again, identifiers. Here's the identifier and the type, and here's the identifier with the value, and you can put it in if it's really small or well known, but generally speaking, they won't be in the future. That allows you to then resolve this type to whatever you choose to say about its semantics, and different people can find different ways of describing it.

There are also, if you're looking to just discover things in this world there's a variety of approaches that one can take to building registries that have this semantic kind of information. I'll give you one example you might just take a look at, not to spend a lot of time on it, because I don't know how much you'll dig up, but there's a site on the net called EIDR.org. It's the entertainment ID registry. I know a little bit about it because we were involved in it at some level, but it's basically the thing that the movie studios in Hollywood and the cable industry in the U.S. are using to identify their assets to manage it to strike deals between each other. It might give you an example of the kind of thing to deal with, and it's all based on identifiers.

Paul Egerman – Software Entrepreneur

So, excellent conversation, although I'm a little concerned that we only have a small number of participants from our workgroup participating, so I think that probably means that I need to move on in the discussion.

Carl Gunter – University of Illinois – Professor

Can I make one quick comment on that one? Paul, ... differences here that I've seen between these domains, you may be quite reasonable to have a unique number for each movie, but it's much more difficult to have a unique number for each medical thing, each disease and each reading and so on. The domains are pretty different.

Robert Kahn – Corporation for National Research Initiatives – President & CEO

Why is that? I don't see it matters exactly what—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I'd like to suggest that we've got 20 years of research into identifying medical concepts. The average medical student learns 100,000 new concepts their first year in school and then they spend the rest of their life learning relationships among them. There's plenty of work already done, we don't need to be reinventing that. We need to be providing a way that people who are accessing data that was created by different people under different representations at different points of time over what could be easily ten years apart, going ten years forward, has a way to understand what formulation was used for medical concepts. We may want to talk about a new name value pair representation for all data, but we don't want to create an environment where all of the tens of thousands of systems in the United States that are creating data using existing standards can't contribute that data to or through a DEAS.

M

I agree. That's why being in the middle working out is exactly the right way to—

M

I think we're talking about defining the middle.

Paul Egerman – Software Entrepreneur

That's exactly right. What I'm asking for some help on is two things. One is, to define the middle. The other is a comment that you made, Wes, about you called the "initial sweet spot set," at least that's what I wrote in my notes. I may not have gotten that right. I think to whatever extent we can give some ideas about what the initial sweet spot is for ONC, I suspect that would be beneficial. So what I'll do is get Wes involved, and Carl, I'll communicate with you over that after the meeting about how we can coordinate that. The basic concept that I have here is the title, what I wrote was "Middle-Out Model" was good. It's like the rest of it, it needs to be fixed, and you guys are going to fix it.

I did want to briefly go back to the top-down model, because I was really curious about something that Bob Kahn said. What you said before, again, I'm not sure I got it right in my notes, is something like you can't do a national model, you need all these individual groups to be doing things. Are you saying this top-down model just won't work if you did this alone?

Robert Kahn – Corporation for National Research Initiatives – President & CEO

No, I'm not saying that at all. In fact, the Internet was created with a top-down model. I just don't think you have that luxury anymore, because you've got lots of different groups that already have establishments in place, they've got systems that they want to work with, and people are going to go and do their own things and pay no attention to what's working at the national ... for a while. What you really need to do is figure out a way to make them all work together. I think you're forced to be in this middle position. Bottom-up can work, too. Bottom-up has got a different set of problems. One is it takes a lot longer to get convergence, and you've just got to work too many things together to make it all play together if you can do it at all. Bottom-up has a much bigger set of problems to me than top-down does. Top-down needs an authority to be able to drive it and probably funding to be able to push it as well. But when you've got an established base and you've got a lot of individual folks out there who don't necessarily feel they need to take direction from the top, you're forced to deal with a system for the middle, I think.

William Stead – Vanderbilt – Chief Strategy and Information Officer

Can I speak for a second?

Paul Egerman – Software Entrepreneur

Absolutely, Bill.

William Stead – Vanderbilt – Chief Strategy and Information Officer

I think the trouble we're having is that you can describe the Internet as a top-down model, but if you elect to do that what you're talking about is a top-down definition in management of the absolute minimum things you had to do to in fact let a bottom-up model do many, many things. I think as written in the report, and I think it's probably useful to have it written that way, the top-down model is actually a complete top-down model. It's in fact trying to do the whole thing top-down. The bottom-up model is the exact opposite, trying to do it all with the market. The middle-out, I believe is actually the Internet model. What are the absolutely fewest things we have to do, top-down, to allow innovation bottom-up. I'll go back on mute.

Robert Kahn – Corporation for National Research Initiatives – President & CEO

I want to just make one observation that I'll emphasize—

Paul Egerman – Software Entrepreneur

I'd like to ask all the workgroup members to state your name before you speak.

Robert Kahn – Corporation for National Research Initiatives – President & CEO

I just want to make one comment about the Internet itself. The Internet to me is not what most people in the public and in the media tend to refer to it as, namely they think it's a network. To me the Internet was designed as a global information system, a way to pass information back and forth so that different kinds of components could all interface and interwork with each other. The Internet to me at that level says you can have any numbers of networks and we don't care what kind they are, you can have any kinds of attached systems and we don't care what they are, but what it does is specify the protocols and procedures that allow whatever they are to work together. So in some sense there's no bottom to the Internet and there's no top. If you were thinking there's something below it, there's just one level of description of all of these protocols.

Paul Egerman – Software Entrepreneur

So it's basically a description of protocols and standards and rules.

Robert Kahn – Corporation for National Research Initiatives – President & CEO

That's why I said top-down you could view the Internet, even that is a totally bottom-up thing, because anybody can do whatever they want in terms of building the components, and people have. It's just that if you use these protocols and procedures they'll all work together.

Gary Marchionini – University of North Carolina – Dean & Professor

Can I just add one little comment here? One, I guess, small concern I have about the description in here in the letter of the bottom-up model is it's very short and it basically says, well, if you don't have any money, do this, if refunding is reduced. I think it would be useful if we ... the challenges or problems. It's not only just slowest. Won't it also lead to challenges of interoperation and other things? I guess I'm a little worried that if there's no money to do top-down, if that's decided, and there's no money to do bottom-up, that this becomes a default and we would get blamed for it.

Paul Egerman – Software Entrepreneur

Let's talk a second about bottom-up. I heard Bob talk before about problems with top-down that requires authority, requires money, and it's like a leadership challenge, where people necessarily respond if you do it that way. What do we see are the relative pluses and minuses of a bottom-up model?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Paul, may I say something? .

Paul Egerman – Software Entrepreneur

Yes.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I hope this is a good time. I think one of the points that's critical to this conversation is that unlike many other things health is really governed at the state level in our country, and as anybody from CDC will tell you, there is no federal authority over health. So I think what we have here is a situation where the states have to be convinced to adopt it at a macro level, but at the same time the vendors and the providers as well, but especially vendors, want to be told specific standards to incorporate in their products. So there's the tensions that we need very specific prescriptive standards to integrate into products and at the same time to have a model that allows a state autonomy that they will insist upon.

Paul Eggerman – Software Entrepreneur

That's—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Yes, and I want a car that goes 0 to 90 in 3 seconds and gets 100 miles to the gallon. I think the sweet spot is about the tension between those two things. Where there is a criterion that must be met in a one or two-year time frame nationwide, such as standards required for certification for meaningful use ONC simply has no choice but to give very detailed and specific specifications. I think that where there is a willingness to seat a process that will evolve on its own, then ONC really I think, based on our retrospective understanding of how the Internet grew, should be encouraging innovation by not blocking it through standards.

Paul Eggerman – Software Entrepreneur

That's actually an interesting way of looking at it. It's sort of like saying, oh, let's look at it from a standpoint of time frame and functionality. So if you need something done in a certain time period you're going to have to be more practiced, probably, to get it done. But if you're willing to take longer or perhaps you don't quite know what to do in some situations and you would like to see multiple approaches taken, then you would like to do a bottom-up model.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I'll bet a dime to the dollar that half of the projects that Bob saw that were over-specified, it was justified based on time frames.

Robert Kahn – Corporation for National Research Initiatives – President & CEO

That could be exactly right. But one other way to think about this that might help clarify it for some of us, if you were to go to ONC and say that we recommend that you develop a one-page equivalent of an elevator pitch. Not as to why you should be part of the system or what its fundamental parameter should be and the like, but this is what you have to do. This is the minimal set of things you have to do to become part of this national healthcare architecture. I'm not talking about the medical certifications, I'm not talking about verifying whether the doctor went to medical school, I'm not talking about whether you understand semantics or any of that stuff, I'm talking about these are the minimal set of things you need to do. I think you can get that down on one page and it would take most of the things that we're talking about here off the table and it would still work perfectly well. You need to be able to interface with the systems with a suitably high protocol, and here's one that's independent of all the detailed semantics, and you need to be able to have a security based on such-and-such. I think there could be a one-page description of what you have to do to take all these issues off the table.

Paul Eggerman – Software Entrepreneur

Great. So what I'm going to do is challenge you guys to get us that one page description, because I think it's a terrific concept. I'm still trying to understand the top-down and bottom-up models, although I think Wes and Gary gave good descriptions of it. In a bottom-up model you're willing to take more time, you run the risk of problems of interoperability, but you also have some independent activities going on that could create innovation. One does not know what that might be. The sum total I'm getting from this whole discussion is the interesting challenge is we're going to end up with all three of these models being used. The interesting challenge is to do what Bob Kahn is saying, well, we'll find the sweet spot, we'll find

exactly the best and the right starting point for ONC so as we iterate through this process we get the thing off to a good start. Is that fair?

Hunt Blair – OVHA – Deputy Director

Paul, I just want to make a brief comment. This has been a really fascinating and useful discussion. I'd just put in again the pitch that one of the sweet spots and points of compromise I think between the tension of states and federal standards, etc., is potentially that state designated entities and state HIEs as a place where both ONC and really to a large extent from a user point of view ultimately CMS have a potentially significant benefit to be gained. So I just will make my pitch because I've got to get off the call now.

Paul Eggerman – Software Entrepreneur

Okay. I appreciate that. We're going to talk about the HIEs in a moment, but I appreciate that. Again, let's focus, because we do need to wrap up this discussion, but in terms of top-down, bottom-up and middle-out it seems like we've got this discussion about trying to find a sweet spot and that sometimes you have to do a little of each. My question is, are there any other comments about this?

Carl Gunter – University of Illinois – Professor

I was wondering if we could add more to what's written—

Paul Eggerman – Software Entrepreneur

I'm sorry, who's speaking right now?

Carl Gunter – University of Illinois – Professor

I'm sorry, Carl on, add more on the question of the incentives in a system, because the PCAST Report, the explicit charge was to use meaningful use to break us out of a situation in which we're stuck. So I think here is the idea you're going to hope it's going to go okay ... bottom-up, is let it fix itself. I think the reports claim that's not going to happen.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I think that a bottom-up strategy, in describing how to do it we're not necessarily recommending it as a choice. That's not our portfolio. But to describe how to do it, it's a lot about getting out of the way. It's not about actively assisting. I don't know that getting out of the way and using meaningful use levers can coexist in the same sentence. So it's possible that one of our conclusions about the bottom-up strategy is that there's less opportunity to use meaningful use levers in an environment where the shape of the DEAS and the UEL have not begun to be seen....

Carl Gunter – University of Illinois – Professor

That was kind of my thinking too.

Paul Eggerman – Software Entrepreneur

Okay.

Gary Marchionini – University of North Carolina – Dean & Professor

I agree with that wholeheartedly.

Paul Eggerman – Software Entrepreneur

Excellent discussion. Unfortunately, based on the agenda I do need to move us forward a bit. I think I have a sense of it based on this discussion. We're going to have some people write up this section and we'll get another iteration of it over the weekend or perhaps early next week.

The next topic on our agenda is just a very general discussion of the report itself. Again, what we're trying to do is the report is in effect a work product from the last three months of our conference calls. We'll be presenting that formally on April 13th. We want to produce it much sooner than that, because we need to get some consensus from the HIT Policy Committee members about it. So what we wanted to do in this segment of the agenda is give workgroup members a chance to just make comments if they're

happy, unhappy, they agree, disagree on any aspect of the report. In making those comments, the one thing I do want to ask is that we make a distinction between wordsmithing the report and actually talking about some concepts. So in other words, I don't want to talk about whether or not we should use "is" or "are" in a sentence. I want to be talking about what are the basic concepts.

Now, unfortunately Hunt had to leave. Hunt sent an e-mail with some issues and also I received a very interesting e-mail from Steve Ondra, who's on vacation this week, who said something similar to what Hunt said. So to tee up the first issue is, what Steve said is, as you look at the report, in a very early part of the report in Section A there are these four comments that are made about the PCAST architecture, and one of the comments that was made is item number three. It says, the existing information exchange work that's been done in stage one of meaningful use, it describes it as "push transactions" and it's listed out and then it says this is foundational, and that work is good work and blesses it and says that, again, we're not replacing that work, so it's like he's reassuring on that point. What Steve Ondra suggested is that that definition of what is foundational is too narrow, that we should include not only the stage one-push transactions, but we should include three other categories of activities.

One of them is what is going on right now with what's called NW-HIN Exchange, which, let me see if I can explain what that is. NW-HIN Exchange is sort of an acronym for information exchange activity involving the VA and DoD and other federal agencies, and some large healthcare organizations. I think Kaiser or perhaps Sutter is involved also, so there's an exchange network in place, so he says well, that's foundational because we're learning a lot. Picking up on what Hunt Blair was suggesting, he said well the HIE organizations are foundational because the same thing, they exist and we're learning a lot. Another category is there's some activities that vendors are doing, so there are some vendors that have done some very innovative work with making data, the customers accessible everywhere to each other, and so that's foundational also. The suggestion that Steve made, which I think is consistent with what Hunt Blair is saying, is that we call that foundational, we reference it here, and then we talk about and we use that same extension when we talk about the path of least regret. I talked for a while, but I want to find out what do people think about that?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I think that's a good idea. I think it needs to be far beyond those three. I think that there's also the Direct Project, there's the SHARP grants, there are lots of things that ONC is doing that we could cite as foundational.

Paul Eggerman – Software Entrepreneur

So what you just said, and other information exchange tests and ... activities?

M

Paul, ... they have the NHIN Direct work, which is what was mentioned, but we didn't mention the NHIN Connect work—

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

That's—

Paul Eggerman – Software Entrepreneur

That's exactly the same as—

M

One of them is a push and the other one is a pull mechanism.

Paul Eggerman – Software Entrepreneur

Yes.

M

Then there's also a lot of work by IHE, for example, a standards body, and then a number of individual HIEs. I think we can list a few of those and say, I haven't seen work that those places are doing where

the feeling is hey, you should stop doing that because you're going in the wrong direction. It's mainly helping towards some additional thing we would do to achieve a national system.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I think you could even include the tiger team There are a lot of things that are supportive of what they recommended.

Robert Kahn – Corporation for National Research Initiatives – President & CEO

I guess I don't really understand what it means to be foundational and the concept of the PCAST Report. If it means that this must be the fundamental part of the system and everything else builds on top of this, I would say that's ill advised. If it means it could be part of the basic structure, I think that's probably desirable. The notion of, for example, push transactions, you may want them for some things. You might want them, for example, in a medical system for making available advisories about some urgent things that are healthcare related and going out to everybody, doctors, patients, whatever, you certainly want pull transactions. I just don't understand what the ... is of saying that the report's recommendations are intended to be built on this foundation and particularly push transactions.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I think that on the one hand we owe it to ONC to describe numerous activities, not to avoid accidentally damning an activity through omission. On the other hand, I think we're approaching the point where anything that has ever talked about health information exchange is foundational. I think that the place in between there where we just can't list everything is to talk about traits of each of several activities that align in some way or another with the DEAS, and the UEL, for that matter. But I think the DEAS is more relevant, the consent system, although I have a lot of reservations about that part of the report. Nonetheless, you can describe the work that has been done under the exchange program in the—what's the name of the software package? It begins with a "C."

Paul Eggerman – Software Entrepreneur

Are you talking about—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

The Connect Project that in fact has generated an experience base for mediating consumer expressed consent information through an intermediation service, so that's foundational. First of all, I think that push is a fundamental means by which business is done, transactions are sent from here to there, and I have a hard time associating anything in the DEAS that is particularly inclined towards that model. On the other hand, the Direct Project did take as a fundamental precept building very closely on existing well-defined, well-proliferated Internet protocols, which has been one of the reasons for its success. I think that is foundational for how we would want to go about building the sweet spot of standards for the DEAS.

Carl Gunter – University of Illinois – Professor

Wes, I agree with this point. Direct was a push mechanism and the report focuses on a pull mechanism, but I don't see any immediate inconsistency because the Direct protocols can be viewed as a transport mechanism that could be a component of some larger thing. So you could perhaps use that transport mechanism in the context of the DEAS under certain functions about how it would work. That's, I think, part of the concept of foundational, which is the transport mechanism is the foundational component. It doesn't dictate the architecture necessarily—

Paul Eggerman – Software Entrepreneur

That's right.

Carl Gunter – University of Illinois – Professor

—... some of the ones that are better than others.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

My main point was just to avoid throwing in every activity that ONC has undertaken as foundational, but to describe some important high attention, high cost activities and describe how they're foundational.

Paul Egberman – Software Entrepreneur

I think that makes sense, because you look at, for example, what you just said, Wes, you look at all this exciting 5010 stuff, the X12 transactions, and I just ... that that doesn't fit the PCAST architecture in any way, but you have transactions that are widely adopted and it's a good thing, right? So we're saying that's a foundational piece because we're not proposing to change that, at least not in the short term.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I am not convinced that pushing is either supported by or goes against the DEAS. I think it's a different model and an important model to fulfill different purposes. There's obviously overlap. Instead of sending a lab result to a physician, I could wait and have the physician wait until they wanted to request the lab result and use the DEAS to do that. Because the availability of the lab result actually triggers an action on the physician to look at it, and if the patient is in any danger waiting to look at it doesn't make sense. It's not a fault of DEAS. DEAS just wasn't intended for that purpose. It was intended for creating whole new approaches to combining and using healthcare information for foreseen and unforeseen benefits.

Robert Kahn – Corporation for National Research Initiatives – President & CEO

Gosh, we could spend a lot of time on virtually every comment that's being made here. Let me just pick up on one comment that was made, I guess by the speaker one or two before this, and that is the idea that we view the Internet as foundational for what's going on in the future. I certainly think conceptually that's a good thing to have in mind, but the real thing that you want to achieve here is interoperability between these very disparate medical health-related systems. There are going to be a lot of them. Today the Internet's really the only choice you have. The Internet's going to evolve, and I think nobody who has been involved with the Internet, no matter what the level of involvement, can tell you with any decision what the Internet's going to look like in ten years or fifty years or a hundred years, or even if it will be around at that point. Yet, when we make an investment in interoperable healthcare systems, you want that interoperability to be with us forever. So one of the things that I think really is important is that you be able to draw on whatever the best capabilities are, not build it into the descriptive architecture of the system, but make it possible for it to adopt and factor in whatever it is that makes the most sense down below.

That's one of the problems with the way this is written, as I read it from cover to cover, that the distinction between what is bound and what is not bound is totally unclear. You'd read it one way and think everything is locked in and the foundational part has got to be part of it, and you can read it and say, well, foundational just means this is how you ought to think about it but it doesn't really pin you down for doing any

Paul Egberman – Software Entrepreneur

Okay, this is very helpful. So picking up on what both Bob and Wes have said, let me see if I can try something on here. Maybe we need to drop this word "foundational." What Wes is saying is we look at these push transactions, we look at ePrescribing, for example, I think possibly is considered a push transaction, and say, well, that's a series of transactions that are actually outside the bounds of what the PCAST Report seems to be reporting, and we need to continue to work on that. That's actually a fair amount of what's going on.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I am not so concerned that we justify everything ONC is doing or advise it to stop things. I am concerned that we not appear to be saying that everything they have done to date is—

Paul Egberman – Software Entrepreneur

Yes, I was going to get to that.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

—... invalid. Okay.

Paul Egberman – Software Entrepreneur

In other words, I'm saying that we're putting this into two buckets or two categories. One category continues to be the widely adopted transactions. The second category, which it doesn't appear the PCAST Report is contemplating, and the second category is these activities like NW-HIN Exchange, some of the SHARP activities, the HIE organizations. So what we say is those are, let me find the right words, but those are critically important projects, to the extent that they are developing concepts that help us enable this vision. So NW-HIN Exchange, to the extent it's developing concepts around, say, query response or some policy issues, that those are issues that we need developed. So those are important concepts and we acknowledge that without necessarily saying it's all foundational, because then it seems like everything that ONC is doing is consistent with the PCAST Report, and that's not quite correct either.

Farzad Mostashari – ONC – Deputy National Coordinator for Programs & Policy

One of the ways we think about this topic here is that there are different building blocks and not every building block is used in every bit, but there are different building blocks and metadata tagging might be a building block. Basic transport and routing protocols may be different building blocks. You may not need that one to do the PCAST kit, if you will, but you may need other building blocks to make the PCAST kit. So you will still need, probably, some method of certificates and authentication or assurance of fair information practices at the end users, or governance for trusted intermediaries, or vocabulary for policies regarding patient choice.

Those are all building blocks that are not automatically dealt with because you have this piece that the PCAST focused on. You still need those other building blocks in place to build what's called the PCAST kit. Then some of those same building blocks will be reused in doing the transaction kit, the Direct kit. So I think there are two concepts there. One is that the PCAST kit doesn't solve all interoperability and exchange needs; and two, that the components that are in PCAST need to work together with other building blocks that are also being developed, whether it's part of the governance rule, whether it's part of our standards and so forth, to be able to work.

Paul Egerman – Software Entrepreneur

Thanks. That's very helpful. In this view of building blocks, let me see if I've got this right, Farzad. The way we could approach these other things, NW-HIN Exchange, vendor activities, HIE organizations, is to basically say these are critically important because they are helping to test or develop necessary building blocks. Is that right?

Farzad Mostashari – ONC – Deputy National Coordinator for Programs & Policy

I think for many of those examples that you list on the bottom of page 12, that that's exactly right. The A through G that you list there on the bottom of page 12 is part of the building blocks concept.

Paul Egerman – Software Entrepreneur

Okay, so the way this is all coming together—at least in my mind. I don't know if there's consensus in the workgroup—is to list out some of these activities, to reference that there are so many more and to be talking about somewhere up in the front, but also in the back that this is where the value is. They are helping us learn. They're helping us create building block components of what we need to do. So that would be how we respond to what Steve is asking for but also what Hunt is asking for. Does that make any sense? Are people comfortable with that?

Farzad Mostashari – ONC – Deputy National Coordinator for Programs & Policy

That was just for informational purposes in terms of helping—

Paul Egerman – Software Entrepreneur

Right. I think what you were saying, though, was pretty close to what I was trying to say. You just said it better. I was comfortable with what you were saying.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I think the notion that there are building blocks in terms of the output of the ONC project is a nice way to describe the contributions of the different efforts. I think it's also worthy of note that the projects have generated operational experience that can be helpful in— Part of the problem with any approach where

you start with standards and then build something is that the more those standards are created in a vacuum the more likely they are to need significant adjustments, to the extent that operational experience generated by existing work helps guide that product, that's a tremendous benefit.

Paul Egerman – Software Entrepreneur

Excellent comment about operational experience. I couldn't agree more. I think we responded to the e-mails from Hunt and from Steve Ondra on this issue. Let me ask the members of the workgroup, Leslie sent out an e-mail earlier. Is there an issue you want to raise, Leslie, or do other workgroup members have any issues? Let me first start with you, Leslie, are you still on the call, or if Harley's on the call?

Harley Geiger – Center for Democracy & Technology – Policy Counsel

Hi, this is Harley. I'm on the call. Leslie is actually feeling pretty sick. She just sent me an e-mail and said she had to get off the call.

Paul Egerman – Software Entrepreneur

I hope we didn't cause that.

Harley Geiger – Center for Democracy & Technology – Policy Counsel

She might not be on for the remainder of the call. We had sent out that e-mail of course. I think that what we're seeing, and she relayed part of the conversation that she had had with you, Paul, is I think that we agree that there needs to be a standard for expressing privacy preferences, both when it's required by law and policy and also when it's not required by law and policy. I think that we all agree on that. But I think that the challenge is expressing it in the letter in such a way that it can't be misinterpreted as making a policy recommendation. I think that's what Leslie was trying to get at in her e-mail and in the comments to the letter.

Paul Egerman – Software Entrepreneur

It seemed to me in my e-mail exchange with her she had interpreted the fact that we would put a privacy tag on a data element as meaning that consent was required for that data element. I was trying to say, no, that's not the way I understand it. You've got to put a privacy tag basically on everything, the architecture, put a privacy tag someplace, on everything. The existence of the tag doesn't imply a requirement for consent. I don't know if people want to chime in on that, but I think that's where the confusion was and I think that's what we need to do to somehow clarify in the writing.

Harley Geiger – Center for Democracy & Technology – Policy Counsel

I think that it really comes down to a matter of wording personally. I'd be happy to talk with you and Leslie about maybe seeing where we can make that especially clear in the letter. But I really do think that it's just a matter of framing it right.

Mark Rothstein – University of Louisville – Chair of Law and Medicine

I had not seen all the latest drafts, I've been travelling around, but one of the things that I noticed relevant to this point is that the language that we use to describe these kinds of situations is somewhat vague and general and arguably ambiguous. I was just asking whether anybody thinks it would help if we actually set out, and it may be in a later draft, so I apologize if that's the case, a list of things that we specifically are not saying in the letter. In other words, have something like the working group takes no position on the following issues deemed beyond its charge; number one, number two, number three. Then we wouldn't have to ... so many things as these issues remain to be decided and so on and so forth.

Paul Egerman – Software Entrepreneur

I think that's one way to do it.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

As a general approach, I would agree. I think the specific issue around consent, though, actually is maybe worthy of specific attention, if only because, and I can't remember the exact citation in the PS report right now, but I believe that some of the illustrative material in the report might have been read by some people as providing a fairly fine-grained model of consent. For example, consent per data element,

well, depending on what you mean by an element, that is a document or that is a specific observation within the document, and that that crosses right at the edge of policy issues and the policy issues discussion is based partly on the feasibility of being able to do that. So I think in that specific area it may be worthy of a special disclaimer.

Paul Egerman – Software Entrepreneur

I agree, Wes. I think that what we need to do is to be very clear about what's going on. The whole area of privacy and consent, it's clearly a sensitive issue. I don't know what the right word is. But if Leslie misunderstood something we said, then that clearly says to me a lot of other people will too and so we need to get that part worded correctly. I do think it's just a wording issue, and it appears you agree, Harley, because I don't think there's any disagreement with what we're trying to say in the report. We're not trying to make any statements at all about—

Mark Rothstein – University of Louisville – Chair of Law and Medicine

I think the wording issue is really very important, because I certainly don't want ONC or any of the readers to get the wrong impression about what we're saying or not saying, and so, yes, it is just wording but it's pretty big time wording.

Paul Egerman – Software Entrepreneur

I agree. I didn't mean to demean it by saying "wording" and so we will work on getting that part correct. What I did want to do is take a minute and turn to your comment, Mark, about you saying that you wanted to write up some description of what we're not saying, is that what you were—

Mark Rothstein – University of Louisville – Chair of Law and Medicine

I was just offering that as an alternative approach to certain areas where we could make a document wide list. Where we could say we're not addressing the issue, for example, of how broadly the information that is available should be used for other purposes, which is a very important thing because the PCAST document certainly makes the argument that these data elements can be used for all sorts of secondary purposes. We didn't really take a stand on that, and that's I think important for us to say that we didn't.

Paul Egerman – Software Entrepreneur

Let's do one at a time. Your suggestion about being clear that we're not taking a stand and part of the way you're suggesting we respond to this consent issue is to simply say it that clearly, that we're not intending to take a position. We need to say that, am I hearing you right?

Mark Rothstein – University of Louisville – Chair of Law and Medicine

Correct, yes.

Carl Gunter – University of Illinois – Professor

It's not quite true. We had a discussion of this at the Federal Advisory Committee hearing and I thought we had a pretty clear consensus on the matter, which was that these mechanisms might be useful alongside, but not in place of the ..., so we did have an important opinion about their role relative to existing programs.

Paul Egerman – Software Entrepreneur

That's feedback from the public as opposed to a position the workgroup is taking.

Carl Gunter – University of Illinois – Professor

I thought that also the workgroup thought that, so there if we're going to say we don't have any opinion on the matter, maybe that's how that was left, but I thought that it was also the workgroup's opinion that we did not interpret the report and did not recommend that this technique would replace existing mechanisms.

Robert Kahn – Corporation for National Research Initiatives – President & CEO

I wanted to make one comment. I think it was Wes that had raised the privacy issue, or discussed it a little earlier, and I just wanted to point out that, quite frankly, dealing with privacy matters ultimately is

dealing with information access control issues. Those are partly technical and they're partly policy, and they really need to be dealt with together because you can't really separate them out clearly enough to know what it is you're actually prescribing.

Paul Egerman – Software Entrepreneur

Agreed. I think we tried to say that in the report.

Stan Huff – Intermountain Healthcare – Chief Medical Informatics Officer

Paul, it seems to me there was a part of Hunt's most recent note that was more directed towards inclusion of mention of state government in Beacon communities and other things. Then there was a note, I think, from Dixie that was in favor of that. I was personally a little less in favor of that. It seemed to me that that, it just didn't seem to fit with me with the flow and what we were trying to discuss primarily from a technology possibility for the new system. It seems like it's in sort of a different dimension of the political and policy and implementation strategies. But I don't know if I'm the odd man out in thinking that.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

My position on that is exactly what I said a while ago. I think that we need to address the state involvement, including the HIEs and the Beacon communities, as we discuss the implementation model. I don't know what that was. Because I think that the states will definitely be relevant in the implementations, but I don't think that that issue is particularly relevant for the specific technology and vocabulary standards that are part of this.

Paul Egerman – Software Entrepreneur

Stan, I was going to respond to that in the redraft related to the earlier discussion. I was going to look at the Beacon communities, the state HIE organizations as sources of these building blocks of new and useful activities. So that's how we would describe them in the front part of the document. In the back part we would also perhaps say this could be a source for testing of private projects, in other words, that there are specific building blocks that we needed tested that could be that the HIE organizations or some of the other entities that were mentioned could be involved in helping with that testing.

Farzad Mostashari – ONC – Deputy National Coordinator for Programs & Policy

Paul, I think on page 13 is where you talk about test beds and pilot projects for that. We actually have, and it could easily be mentioned, we have funded breakthrough supplemental grants to states for investigation of these kinds of activities.

Paul Egerman – Software Entrepreneur

That's where I'd picture working them back in. So in other words I saw them in the front, acknowledging that they're playing a critical role, and also acknowledging that the other PCAST Report says don't rip and replace. We're not trying to rip and replace these activities, though they may evolve over time like everybody else. But acknowledging them in the front and then putting them exactly, as Farzad said, somewhere back here where we talk about this iterative process of test beds that these, I mean, it just makes sense because they have a lot of the infrastructure already in place to do all of this testing.

Tim Elwell – Misys Open Source Solutions – Vice President

Paul, just one comment on this. I think that we've got to be real careful from the standpoint of this is a point in time and although these are considered to be successful implementations today, if we set the marker as being today, we don't want to be exclusive of any innovations tomorrow. So I do just want to make sure that if we reference things like Beacon communities or even the existing state exchanges today. There are many states that don't have any exchanges today and there's also technologies that are being developed that in some cases are different than what has already existed or been implemented that actually may be quite innovative. So we want to be able to invite that type of participation going forward. So by example that's great, but I don't want to indicate on the report that that's—

Paul Egerman – Software Entrepreneur

....

Tim Elwell – Misys Open Source Solutions – Vice President

Exactly.

Paul Egberman – Software Entrepreneur

That's an exclusive club. That's a very good comment. I appreciate that.

Stan Huff – Intermountain Healthcare – Chief Medical Informatics Officer

Yes, I think that gets at the heart of what my concern was, is not that they couldn't be one of the options, but the idea that the report would be biased, that those are the only places where this kind of experimentation and creativity could occur.

Paul Egberman – Software Entrepreneur

So, in other words—

Stan Huff – Intermountain Healthcare – Chief Medical Informatics Officer

Yes, I'm comfortable with how you responded.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Dixie raised an important point, I'm not sure whether it's relevant to this actual report or not, but there is a lot of the innovative approaches that I think Tim was alluding to, and certainly the ones I've been recognizing in my writing are not state specific, they're national in scope. In fact, if I was to take one feature of the general thrust of the PCAST Report and compare it to the existing state cooperative agreement program for health information exchange, it is more of an emphasis on national scope connectivity.

I want to recognize that the influence of the states, particularly around policy, is a critical part of any attempts to get to the kind of wide Internet value associated with the DEAS and the UEL, and that I believe there's at least implicit or tacit recognition that that is part of the challenge of the DEAS. That in fact trying to extract the focus on this specific issue, the implication is that it's not necessarily to have state organized health information exchange to recognize state policies with respect to health information exchange, and that instead that's just the challenge in doing the report. Because I think if there's one thing about the PCAST Report that can be contrasted to the vector that ONC was on when the ARA bill was originally passed, it is a shift towards acknowledging the state role without necessarily relying on the states to solve the problem.

Paul Egberman – Software Entrepreneur

That's helpful. Based on that comment, is there something different we need to do in this report?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I just want to be careful we don't introduce any wording about states that implies—it's almost the same argument we had for the Beacon grant.

Paul Egberman – Software Entrepreneur

Okay, I understand what you're saying now. Thanks.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I think we need to recognize as we write up, especially these models, this is Dixie, that we do have to deal with state policies. If you look at public health today, when you investigate an outbreak, for example, some of the states will not allow their health data to flow over state lines. So you've got to recognize that that health policy is at the state level as we write up our report. I totally agree with Wes. This isn't to say you have to implement the DEAS' at a state level, that's not to say that at all, but that as we implement any of these ... we have to recognize that.

Paul Egberman – Software Entrepreneur

What's the way to do that? I'm hearing what Wes said, well, technology you can have an actual technology and still implement the state and the local—

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

... and that recognizes and allows state policy—

Carl Gunter – University of Illinois – Professor

I thought about this, in looking at the design the metadata tags could be created so that they reflect state law, for example. So when you create a data item with its sharing rules, those could reflect the laws of the state in which the data had—

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes, good point.

Paul Egerman – Software Entrepreneur

I agree, and I'm glad you said that, Carl. My question is, could we put some clarification to Appendix B, which you did a terrific job of writing, to say exactly that?

Carl Gunter – University of Illinois – Professor

Sure, that would be no problem. This is actually a great segue for a point I wanted to offer. ... Leslie's note and the suggestion she made in the document. It didn't seem to me quite true that the PCAST Report makes no policy recommendations. To me there's an underlying implication that we need to move more towards a federal system, of course consistent with state rules, but that policy should shift away from a jumble of state programs to a national program.

Paul Egerman – Software Entrepreneur

Whether or not that's what the PCAST Report does, the important thing is that our report make no policy recommendation.

Carl Gunter – University of Illinois – Professor

Yes, I didn't see in our charge –

Paul Egerman – Software Entrepreneur

Yes, and our charge is not to tell anybody how to fix privacy policy or to deal with the federal state stuff.

Carl Gunter – University of Illinois – Professor

Yes, but when Leslie was on the call I took the charge there to be that we couldn't claim that the PCAST Report make policy recommendation, and I didn't think that was true.

Paul Egerman – Software Entrepreneur

I do think that's what she was saying, but we can ask her. She's apparently gone home ill or something.

Carl Gunter – University of Illinois – Professor

Okay.

Paul Egerman – Software Entrepreneur

And I hope it's not caused by metadata.

Harley Geiger – Center for Democracy & Technology – Policy Counsel

I'm not sure that's what she was saying. I think that she was really referring to privacy policy specifically, not all policy in general.

Carl Gunter – University of Illinois – Professor

Yes, I think that was the—but it did make me think it is the case that there are recommendations of policy in the PCAST Report, or certainly implications of that. I didn't see in our charge that we're asked to make—

Paul Egerman – Software Entrepreneur

That's right.

Carl Gunter – University of Illinois – Professor

—... of policy decisions. We're supposed to offer alternatives, but that doesn't mean the PCAST Report didn't have implications for policy.

Paul Egerman – Software Entrepreneur

That's right. Let's return to our report a minute. We've talked about a number of issues, I want to find out, though, do people have any other issues that we haven't raised yet that they want to talk about in the report?

Eileen Twiggs – Planned Parenthood Federation of America – Director

Paul, I just want to raise one thing that I was struck by when I was reading. I feel like in a lot of places we talk about the need to develop standards around metadata and then we also speak about the need to further develop privacy preferences and rules and things of that nature as it relates to patient consent in other places. But the thing that I don't think we've specifically touched on, which I feel we did discuss and it's probably worth touching on, is that we really do need to develop a privacy framework for metadata. So to understand how metadata is to be used and what treatment, how it will be protected in the event that the metadata actually has either identifiable or sensitive information embedded within it. So I thought that that was one area.

There were two places in the report, and I'd be happy to provide some suggested language where I thought we might call that out specifically. One was in the appendix, where we talk about metadata regulation, we have four bullet points there I thought we might just add another. Then the other is in the middle-out model where we talk both about developing standards for metadata and developing rules that reflect privacy preferences and things of that nature. I felt like that might be a nice place to tie in this concept of establishing a framework for the treatment of metadata.

Paul Egerman – Software Entrepreneur

Yes, and it's an excellent issue, because you're right, in the appendix, I think it's D—

Eileen Twiggs – Planned Parenthood Federation of America – Director

Yes.

Paul Egerman – Software Entrepreneur

—... we actually have a couple of sections about metadata, but there was one on basically metadata regulation. That appendix, it's easy, it's great, because basically all we're doing is spotting issues, we're not making a decision about them. So if you have something you want to add there—

Carl Gunter – University of Illinois – Professor

I put a bullet related in the technology discussion in the gap analysis saying that one of the challenges here is how much information DEAS is going to have because of the metadata. Maybe we can elaborate that a little bit to say that there's a challenge with the privacy management of the metadata.

Robert Kahn – Corporation for National Research Initiatives – President & CEO

Again, I think we're trying to tease apart parts of what are technical and architectural into separate categories, when a common unified approach I think would work. We're talking about metadata and just one component of this digital information at large and if it's got identifiers to the information, it's easy to get to the metadata, and it can all be represented in a common structural way or mapped into one. So when we're talking about the need for privacy in metadata, I believe we've got the same issues about privacy for the actual informational content itself, privacy for transactional data that may be kept about the information, which I wouldn't call metadata. Then you've got issues about privacy for identifiers themselves, which has come up in many contexts, including at the national level.

So I think one can state that one is concerned about privacy in each of these cases, and as I said before, I think it links into access control. But I think a unified approach can deal with all of them rather than

having to say well, we need an approach for this one and an approach for that one, we need to treat all of them, and we can state that. But I think we can do it in a much more unified fashion than perhaps most people realize.

Carl Gunter – University of Illinois – Professor

One thing I wonder, and John Halamka brought this point up earlier, is I'm not sure that some of the problems that come with this DEAS search can default, so that there's a little bit of an implication I was picking up from Bob that this is all solvable, and I'm not sure that's true. So for example, if I'm searching for whether there are HIV results on Carl Gunter and I get back something, I don't care necessarily what the results were, just the mere fact that such a piece of data exists and is searchable and it has privacy implications. So there are some fundamental questions about the information flows here that have to be answered that are not just a matter of coming up with a standard.

Robert Kahn – Corporation for National Research Initiatives – President & CEO

Carl, that in turn is an access control capability on metadata registries, so assuming that this is all information that you're trying to access that would be one of the things you'd want to control. So the fact is, this registry says, look, I'm not going to tell you anything about patient Joe Blow because you're not authorized to hear anything about it. Whatever privacy would say about that could be embedded in that registry, it could be embedded in repositories that keep the data, it can be embedded in resolution systems that will allow you to go places that you should or shouldn't be allowed to go.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Privacy protection I think we all know is a lot more than access control and, as I think Carl is implying, there are also the ... reporting ..., there are aggregation and inference problems as well, and I think the consumer does have a right to seek what can be gleaned from that DEAS.

Robert Kahn – Corporation for National Research Initiatives – President & CEO

I agree with that. I just think that they're intermittently tied together.

Carl Gunter – University of Illinois – Professor

One thing I really like about the PCAST Report is the kind of can-do attitude for trying to improve the healthcare system, and I don't want to throw any cold water on that, but some of the ... question whether they can be done.

Paul Egerman – Software Entrepreneur

Let me start the discussion with a comment that Eileen made. I just want to be clear. What I'm suggesting that Eileen do is go ahead and make her proposed change to, I think it's Appendix D, and that Carl suggested there's some wording in Appendix B she should probably look at. If you want to propose, Eileen, something for the middle-out section, that would be great. Just realize middle-out seems to be like a bit of a work in progress, whatever you propose, the sentence might disappear that you're proposing to change.

Eileen Twiggs – Planned Parenthood Federation of America – Director

Understood.

Paul Egerman – Software Entrepreneur

But if you propose that, at least I can understand where you're coming from, because I just want to make sure that we accommodate what it is that you are saying.

Robert Kahn – Corporation for National Research Initiatives – President & CEO

Unfortunately, I have some other commitments. I'm going to have to get off the call. But I will get you stuff as promised in the next few days, or certainly by the weekend at the latest.

Paul Egerman – Software Entrepreneur

That would be terrific. It's great what, I think Carl, or I forget who said it, maybe it was Carl who said that the PCAST Report has a can-do attitude and if you can tell us how to do the whole thing in one take, that's really can-do.

Robert Kahn – Corporation for National Research Initiatives – President & CEO

I don't promise, but I'll—

Paul Egerman – Software Entrepreneur

I'd love getting everything done in one page, so that would be great. Thank you, Bob.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I understand your concern about the agenda, but I just have to get on my soapbox here. We have to recognize that one of the audiences for our report is CIOs and executives and policy people in healthcare that are familiar with the 40 year experience of the hubris of technology companies that their technology is going to solve the IT problems of healthcare, it's just that healthcare doesn't know how to use it. Everything from the, what's his name now, the guy who founded the original browser company Netscape doing a big dot-com in healthcare and at the end saying he'll never do another project in healthcare again.

M

Mark Andreesen?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

No, it wasn't Mark. It was the executive, Jim Clark or something. But the fact is that maybe this time they got it right, but in fact we can't be blessing the blind faith of technologists unless we're really convinced. When it comes to this area of having DEAS' administer privacy consent, I think it's a fundamentally flawed approach and I think that we've heard that over and over again from a number of people who have testified. The notion that it's all a registry, well, maybe, but we've got a lot more specific examples to go through before I'd be convinced of that. Just the fact that Carl used himself in the thing, so just the fact that Carl had a registry entry that said that he wanted to block HIV entries is itself information that can't be made public. We have to go through these, if there's any belief that the notion of centralized multiple private DEAS policy engines are going to solve granular consent problems, then we need to be recommending actions to bear down on that concept.

Paul Egerman – Software Entrepreneur

Those are great comments, Wes. I'm really glad you're on what you called your soapbox. Excellent comments, because it gives us a good transition into the last agenda item, which is I wanted to talk about what I call our concluding paragraph, which is what do we really want to say. But before I do that, I just want to say we've got this body of documents called the "Report before the Concluding Paragraph," and I realize we've got a little bit of work to do on this whole middle-out area. We've got some wordsmithing to do, but am I correct in assuming that there's consensus in the workgroup that the content of this report, assuming you can look at the final copy and view that the content of this report is correct, this represents our work.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I need to see another version. I sent a lot of comments in that are things I really care about that we haven't necessarily discussed here. So I'm not ready to do that.

Paul Egerman – Software Entrepreneur

Okay.

Richard Platt – Harvard Medical School – Professor & Chair

One thing that I would like the report to say more clearly, or to identify more clearly, is the need to understand the needs of talking to the people who will be using the data for population ... purposes.

Paul Egerman – Software Entrepreneur

Richard, can you speak up? I'm having a little trouble hearing you.

Richard Platt – Harvard Medical School – Professor & Chair

Yes. From the perspective of those who will use the information for population health purposes, it will be important to better understand their needs so that as the specifications are developed and the system is further designed those needs can be addressed along the way.

Paul Egerman – Software Entrepreneur

So we need to do what?

Richard Platt – Harvard Medical School – Professor & Chair

Well, we need to understand the needs to support the various population health uses that are addressed. I think the right broad categories of uses are identified, but it will be worthwhile to make some explicit statement about the importance of doing a real technical needs assessment to be sure that those are incorporated into the decisions that are made.

Paul Egerman – Software Entrepreneur

Okay.

Carl Gunter – University of Illinois – Professor

I thought of another thing to add along those lines, which I mentioned earlier, was somewhere in the report to say that it's not viewed as the mechanisms proposed are intended to replace, for example, federated systems of research analysis or other approaches people are using now where it would be hard to see how you would do those things using these approaches but intended to supplement them in ways that one hopes to

Paul Egerman – Software Entrepreneur

Carl, okay. I agree. I'm just trying to figure out where do we say that, where should we say that in the report? Do we put that in Appendix B also where we're explaining the report?

Carl Gunter – University of Illinois – Professor

It can go into Appendix B. It's a little more of a policy-oriented thing than a technology description. Appendix B is a little more like what is the capability they're proposing, where it's a little more like a clarification of the role of those capabilities in a broader context. I'm not sure where it goes.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

It might be in Section A, which is the summary of the PCAST Report.

Carl Gunter – University of Illinois – Professor

Yes, maybe in the summary of the PCAST Report one could say that it's not intended to eliminate existing

Paul Egerman – Software Entrepreneur

Okay, I appreciate that suggestion, Dixie. That makes sense. Before we go to the concluding paragraph, does anybody else have any issues with the report?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Paul, I'd like to have this group hear the opinions of others on the assertion in the policy section that says that they recommend integration of EHRs and PHRs, that you and I have had some discussion about.

Paul Egerman – Software Entrepreneur

Yes, so let me see if I can frame that issue. What we said in Appendix D was that our reading of the PCAST Report said that EHRs and PHR data would be merged together, and you, Dixie, said no, that's incorrect, that you don't see that it says that.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

No, I don't.

Paul Egberman – Software Entrepreneur

Here's how I was going to fix that to get everybody happy, is I was going to say something was if the PCAST Report is interpreted to mean that they're merged together, then there's a policy issue. Apparently some people interpret it that way, and if that's correct then there is a policy issue.

Gary Marchionini – University of North Carolina – Dean & Professor

This is one of the things that I was concerned about in that subgroup. I'm not sure that they've been merged as much as there seems to be an underlying assumption that, well, there was focus on EHRs and PHRs were mentioned and I think I did a word count and current count it was something like 14 times in pretty critical places, almost like an after-thought of, that will work for PHRs too. But they really are substantially different in terms of how people think about owning that data. So I think what we did is we came up with that notion of them being merged. Although it was I think perhaps more that in the PCAST Report the overwhelming focus, probably rightfully so, was on the EHR solution, because that's what ONC and meaningful use is really focused on. But I think we have to say something about PHRs here and I'm not married to the "merging" word if we can find a better way to—

Paul Egberman – Software Entrepreneur

I think I can handle what you're saying and satisfy what Dixie's saying, so let me work on that.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

My concern is that providers, all of them would go ballistic if they think that PHRs and EHRs are actually merged. I think the report every time, and I did search throughout the document, every time it mentions the term "PHR" it's consistent with our concepts of PHRs today.

Paul Egberman – Software Entrepreneur

Okay. Does anybody else have any other comments about the report?

Steven Stack – St. Joseph Hospital East – Chair, ER Dept

Dixie, you're correct the providers would go ballistic if they felt that there was an unauditable blurring and mixing and integration of those sources without a very clear identifiable trail as to where the information came from and from the provider still being able to have control over determining what to actively include or exclude from their personal EMR. Because I think it would make their data management life impossible to manage.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes, and related to that, Paul, is the point that Bill and I and you had a little exchange this morning. The report says that if a provider pulls information from the DS and they pull the encryption key and they decrypt it and they can view it, then the key goes away and they can only retain it in encrypted form. So the implication there is that that information would never be integrated with an EHR, and I think that if a provider made a clinical decision based on the information that they viewed, they would insist that that information be persisted as part of that patient's EHR just to document the data upon which that decision was made. I think somewhere in our report we should mention that the whole fleshing out of that concept of pulling data, looking at it, and not persisting it really has not been fleshed out well.

Steven Stack – St. Joseph Hospital East – Chair, ER Dept

Not to prolong this, but Dixie I would agree with you. I think you've identified two separate corridors on either side of the issue, which are, the providers, I think, to the individual clinicians would insist upon, one being able to retain the active ability to determine what they will or will not include in their EMR. But that also, two, if they import information that they rightfully have access to and are authorized to see and then they base clinical decisions off of it, that they would also insist that if they appropriately accessed it that they should also retain the rights to be able to import it and preserve it in their EMR.

Now PCAST may envision that it is possible to have enduring privacy tags that make sure that the clinician doesn't further disseminate that information electronically. But the clinician or the institutional

provider would have to maintain it in order to substantiate the services they provide and/or the rationale for any potential legal reasons in the future.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Right, which is kind of a CRM model. That's not in the report. It just says that they would either destroy the encrypted data or they retain it encrypted.

Paul Eggerman – Software Entrepreneur

It's an interesting issue. Where do you think we should make this observation? Is that a policy issue that we could refer to in Appendix D?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I just have a comment. I don't understand how a doctor would defend himself with data that he can't unlock.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes, good point. He can unlock it, but he can't retain it.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

What does that even mean? The theory is I was able to unlock some data, I looked at it, I made a decision, I store it, but I store it encrypted, which means I need a DEAS to give me permission again to look at it to show it to my lawyer.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Right.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

But the patient has since withdrawn consent.

Paul Eggerman – Software Entrepreneur

So here's what we'll do. We'll write this up, we'll put it in Appendix D, and since you raised it, Dixie, would you mind writing a paragraph that describes it?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Sure. Yes and I'll include both of the points that whoever was just speaking mentioned.

Paul Eggerman – Software Entrepreneur

That was Steve.

Carl Gunter – University of Illinois – Professor

A lot of these topics are getting awfully detailed. These are the kinds of things that—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I don't think that—

Carl Gunter – University of Illinois – Professor

I think some of these things are quite resolvable if you work at it.

Paul Eggerman – Software Entrepreneur

That could be.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I think we have a serious problem about blithe assumptions in a PCAST Report.

Paul Egerman – Software Entrepreneur

That was a good comment, Wes. Let me respond at a general level. One is that with what we put into the appendix we said we're spotting issues. We also said we knew we didn't spot all of them. So we don't have an obligation to spot all of them, but if there's an issue that people think important, that Dixie and Steve Stack think is important, I think that there's no reason why we can't put another paragraph in to satisfy them.

But I would like to turn, looking at the clock, to the other agenda item, which is a concluding paragraph. Because I get the sense, from Wes and a few other people, that there's some concerns here because this is a report and there's a big difference between a report and a concept and putting something in operation. The way I look at what we've done in our report, one of the things I think is to not lose the forest for the trees. There's a very important concept in the report, an important concept that came out of Bill Stead and the Implementation Taskgroup's work, which is to say you can do an incremental rollout of this process, where one stage builds on the other and you need to build working models to work out these issues.

That's an important concept in that it's still consistent with moving aggressively. You can move aggressively and still increment. In some sense, there's no choice. You can't implement a national system based on a theory. You have to have some working models. So the question is, for the concluding paragraph is there something that we want to say about this situation that can somehow bring us all together, where some people think these issues can be worked out. Some people are skeptical, and it sort of emphasizes we need to build working models, is there some way we can do this in our concluding paragraph that makes it clear that you need operational experience?

William Stead – Vanderbilt – Chief Strategy and Information Officer

We discussed these at the hearing, and I agree with Carl giving a smidgen of detail. There are many ways that you could address the question that's just been discussed. For example, you can either say the DEAS has to be able to recreate something once it's been used, or that the provider has to be able to record it. I think where you're headed right now, Paul, is correct. What we need are test beds to see which of those and other possible approaches are in fact workable for meeting the provider's legitimate needs. I'll go back on mute.

Paul Egerman – Software Entrepreneur

Okay. My question is this, we're going to have a concluding paragraph, what are the one or two things we want to emphasize? Is it that we need operational experience? What do we want?

Carl Gunter – University of Illinois – Professor

Paul, I have a couple of ... things. One is what you said, which is that we need to be able to do things in steps. But also that, again, I'll go back to this "can-do" phrase, the idea of an advanced national infrastructure for health information exchange for the purposes of improving care is a wonderful objective and is an opportunity to move ahead with something. It's very exciting with a proposal on the table that has a lot of good elements in it. It's like a positive attitude that will lead to something being accomplished if we can manage it.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I think that we could say that, and I agree with Wes actually, I think the ... has decided this report is not workable while delivering safe, quality care. But I think that we should say that from a technological point of view, just everything described in there is possible, is doable. From the perspective of clinical operations and the efficient delivery of patient care, some of these concepts need to be rethought and alternative approaches need to be developed.

Mark Rothstein – University of Louisville – Chair of Law and Medicine

From my perspective the PCAST Report, if implemented, would not be very helpful to the advancement of health privacy. I think there are innumerable problems that would be raised by a system along the lines that they recommend. Nowhere in the report, or in our report, because it's not what we were asked to do,

did the working group say whether we feel that the approach suggested by PCAST is a good one or a bad one. We've got lots of public comment about that, but we haven't drawn any conclusions. I would like to have that sentiment clearly reflected in the conclusion.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Which sentiment, that we're not allowed to draw a conclusion?

Mark Rothstein – University of Louisville – Chair of Law and Medicine

Yes.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I agree. I think keeping in mind our brief, which is to present options for advancing the PCAST Report, is important. I'm willing to, even though I don't feel it personally, I'm willing to shy away from phrases like ... of the technology But I think that in our recommendations that whatever test beds we talk about need to bear down quickly on the issues of validating the technology for maintaining patient consent by the standard of whether healthcare providers and healthcare consumers are willing to allow their patients to be shared that way. Fundamentally, the one thing we know is that healthcare providers have lawyers and persuading the lawyers is as big a challenge as anything else. And it doesn't matter how good the technology is, if we don't do that I actually believe that if one were to criticize the report, one might criticize it in that area. But I'm suggesting that how to advance is to suggest close attention to that area.

Gary Marchionini – University of North Carolina – Dean & Professor

I want to reiterate and build on Dixie's point about even though technically this is feasible and it's bold and wonderful, that the whole system is going to be very opposed to adoption. It's not just the healthcare system. It's actually patients and individual providers who, just the whole human factors of making such change is going to take some time. So this urgency to move this ahead is mitigated by just the human inertia of adopting a different way of thinking about something that's so critical and personal as their health records.

M

In a way that's the yin yang of it, which is to say that the yin is—I don't know which is yin and which is yang, but we're dealing with opposing factors of history and cultural reluctance to risk change. Those are in part embodied in policy, but there's no reason to believe policy is simply cultural resistance to change. We know historically that if you simply ask people, do you want your data to be shared, they say no. If they have some benefit to be achieved by having their data shared, then they make a studied opinion, but there's no reason not to say no if there's no value.

Carl Gunter – University of Illinois – Professor

If you ask, would you like your data to be available to your provider with your consent, I bet you'd get a very high percentage—

M

Yes, but that's not the value proposition that the PCAST Report is based on.

Carl Gunter – University of Illinois – Professor

Why not? Because here's—

Paul Eggerman – Software Entrepreneur

Here's a way that we could do this. I'm listening to this and trying to absorb it. It seems like a comment that was made, I can't remember if it was Mark or Gary who made the comment, I think it was Mark, concerned that, gee, we're not really advancing the whole area of privacy and consent. So, one of the ways that we can perhaps deal with this in a concluding paragraph is make the observation, as somebody did, that public feedback expressed that viewpoint and that that would be something that would be advisable to do.

M

I think, we're in the last paragraph now, okay, we can definitely acknowledge public feedback, and I think we can identify that absent trying it it's difficult to extrapolate the mechanisms that are provided to the complexity of getting data authorized to be released with consent.

Carl Gunter – University of Illinois – Professor

I think by making data available you protect privacy. But the goal is to make data available when it's needed consistent with reasonable privacy So I think you're always going to find that taking the data and destroying it is going to help preserve privacy or hiding it or whatever, that the challenges here lie in these

M

My point is who gets to make the judgment of what's reasonable? We believe that it's the healthcare providers and their patients.

Richard Platt – Harvard Medical School – Professor & Chair

I think if we were talking about measuring quality of care it's probably not the providers and their patients. Yet, I think we would likely find great consensus that it's important to be able to measure quality.

M

Yes, the report certainly doesn't advocate that the providers are in charge of that.

M

The providers will not release data to a general use mechanism unless they believe that their ability to express the consent given by their patient is being forced, period.

Paul Egerman – Software Entrepreneur

Let me raise this discussion to a slightly higher level, which is to say what I'm hearing in terms of concluding paragraph is I'm hearing a couple of things. One is, we have a lot of privacy concerns, which is a recurrent theme in the document. That was what was in the public feedback. We say that for when we talk about the top three policy issues, and so it's perfectly reasonable that somehow in our concluding paragraph we say that. The privacy concerns, and we said that earlier, critically important because they have to be addressed because that has an impact on everything, absolutely everything, right, adoption, patients, physicians. You used the word "foundational" before, but if anything's foundational it's this issue.

Eileen Twiggs – Planned Parenthood Federation of America – Director

Paul, I completely agree with that, and I actually think that, people may not agree with me on this, but I think the PCAST report recognizes that quite clearly.

Paul Egerman – Software Entrepreneur

There's just skepticism among some of the members whether or not it's effective.

Eileen Twiggs – Planned Parenthood Federation of America – Director

Yes.

M

I would say that recognition has to be balanced against their imploring ONC to move forward rapidly.

Eileen Twiggs – Planned Parenthood Federation of America – Director

Yes, absolutely. I do think that their approach actually complicates the, I mean, we currently have privacy issues when it comes to healthcare that remain unresolved, and this approach, I think, actually just adds in layers of complexities to resolving those issues, and then there's the ... issue as well. I agree.

Carl Gunter – University of Illinois – Professor

I think it finally cuts two ways. There are things, like the DEAS' query mechanism is pretty edgy as far as privacy concerns go, and I think that I reflect some of those skepticisms Dixie and Wes have expressed.

But it's also the case that some elements of the approach, like the privacy tags could be a foundation for better sharing of data with better privacy. So I think it's not true that this report does not have elements that advance privacy considerations. Right now we don't have persistent privacy tag data, it's all left up to basically manual decisions of providers, and so having the idea that there would be a privacy tag

Paul Egerman – Software Entrepreneur

That's good, Carl, but in some sense it's a benefit that we have that we aren't required to make a judgment. All we have to do is say this is important.

M

A lot of times, even now—

Carl Gunter – University of Illinois – Professor

... judgment, we say that there are all these privacy problems.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

There are privacy questions that need to be answered through operational sites, and we can emphasize that in our concluding paragraph.

Carl Gunter – University of Illinois – Professor

That I absolutely agree with.

Paul Egerman – Software Entrepreneur

And I'm trying to say that as broadly as I can. There are lots of components to it. We've talked about what some people thought was too detailed about what happens when somebody changes a preference, but also there are components of, can patients handle it? ... Steve Stack's still on the phone, and there's the provider components. This is huge.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I'd just like to ask anybody, but particularly Carl and Dixie a question. Do they believe that the decision to unlock data is implemented by some agency, and I use that term not to mean a federal agency, but just some organization's technology that is not the original source of the information, or not? My reading is that the DEAS assumes that the operator of the DEAS is trustworthy to be an honest broker on the decisions to unlock the data.

Paul Egerman – Software Entrepreneur

I think that's too detailed a question right now.

Carl Gunter – University of Illinois – Professor

... give you my list of options of what I thought—

Paul Egerman – Software Entrepreneur

I think what we want to do is we want to understand the broad issues. One broad issue I'm hearing is privacy. Another broad issue that I heard—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

The reason I was raising that, and we don't have to discuss it now, but it seems to me that at a very fundamental level the PCAST Report is distinct and counter to the principles of fair information practices that the tiger team is developing.

Paul Egerman – Software Entrepreneur

Well, I don't want to go there. It's an interesting discussion, but that's a different argument.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Yes.

Paul Eggerman – Software Entrepreneur

What I want to simply say is there's an aspect here on the privacy side that the ONC needs to demonstrate.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I just don't want that to be a tepid comment. It has to be expressed with urgency and immediacy.

William Stead – Vanderbilt – Chief Strategy and Information Officer

I think we've got a challenge in that we've actually done a pretty good job of stating the things as we've gone through the report, and so our trick is how we make a very small number of points in this concluding paragraph. I believe that the first point is there are major concerns involving policy. You can make that privacy if you want to, but there are many concerns, and feasibility. To me that's one point.

A second point is that an aggressive course is possible, but that it requires test beds to resolve the concerns. It is hard. I don't know how much else we can say in a concluding paragraph that we've not already said.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Here's a suggestion—

William Stead – Vanderbilt – Chief Strategy and Information Officer

Wes?

Paul Eggerman – Software Entrepreneur

If you've got a little bit more to say, Bill, go ahead. Were you done? Did we lose you?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I think he went back on mute.

William Stead – Vanderbilt – Chief Strategy and Information Officer

Did you ask me something? I'm sorry.

Paul Eggerman – Software Entrepreneur

You said two things. One was—

William Stead – Vanderbilt – Chief Strategy and Information Officer

There are substantive policy and—

Paul Eggerman – Software Entrepreneur

—feasibility issues.

William Stead – Vanderbilt – Chief Strategy and Information Officer

—and feasibility issues. The technical—

Paul Eggerman – Software Entrepreneur

Then you talked about as aggressive a schedule as possible that requires test beds. Was there a third one, or were those the only two?

William Stead – Vanderbilt – Chief Strategy and Information Officer

Or maybe you break the last into two. I think at high level those are the three points. If we could get something that high we might be better off.

Paul Eggerman – Software Entrepreneur

I just want to make sure, major concerns about policy and feasibility, that's one; aggressive is possible, but requires test beds, that's two.

William Stead – Vanderbilt – Chief Strategy and Information Officer

Or maybe aggressive progress is possible through an incremental approach, definition and test beds are required to address the concerns.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I think the test beds certainly are needed, pilots are needed for the technology, proof of feasibility, etc. But I don't think that that's the real issue. As I said before, I think from a technological perspective this is all feasible. What I think the barriers are, are operational barriers and the very fact, Wes has mentioned it before, the healthcare industry is very litigation driven and there are just fundamental operational issues, workflow issues, the way healthcare does business, that are the real issues.

Paul Egerman – Software Entrepreneur

Bill said policy and feasibility.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I agree with that one. It's the second one. I don't think that test beds—

Paul Egerman – Software Entrepreneur

I want to go back to policy and feasibility.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I agree with that one.

Paul Egerman – Software Entrepreneur

Feasibility, is that the same as these operational issues?

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes, operational feasibility, yes.

Paul Egerman – Software Entrepreneur

Okay. So policy and operational feasibility is the first issue that there are major concerns. The second one is aggressive is possible, but it requires these test beds.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I think the definition of test bed is important here.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Yes.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Too many test beds simply demonstrate that the technology works. What we are implying, I think, is that as ONC has already done with the Direct Project, it needs to define the success of test beds in terms of operational use of them, rather than a demonstration. So the test bed isn't useful—

Carl Gunter – University of Illinois – Professor

... distinguishing between—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Unless it shows operational feasibility with real live patient data.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

The term "test bed" sounds like a technological—

Paul Egerman – Software Entrepreneur

You need to have a large operational experience.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Pilots, yes. Pilot would be better.

Carl Gunter – University of Illinois – Professor

One thing that's missing from these two parts is some explanation in the conclusion of what the end goal is. What are you trying to accomplish with this? It seems like on a national scale health information exchange system benefits patient's care with the adequate privacy protection the end goal. We're not saying anything about what is to be achieved—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I agree with Paul that that paragraph needs to set a goal, but I think that the phrase "that benefits patient care" would really be seen by the authors as limiting. In the broadest sense it's about a learning healthcare system, it's about new businesses that are created by combining information that's available through the DEAS. It's about a whole number of things, all of which can be traced back or traced forward to some benefits of patient care. But it's about health as opposed to care. It's about knowledge. It's just about a whole bunch of—

Paul Egerman – Software Entrepreneur

The goal part may be the easiest part of this discussion, believe it or not, because I would say the goal is to facilitate the learning health system described in the ONC strategic framework. So that part—

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Yes, that's good.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

And we can even agree with that goal.

Paul Egerman – Software Entrepreneur

Yes, because—

Carl Gunter – University of Illinois – Professor

Plus it's a bad way of describing the goal, so maybe I didn't get a good phrasing of that. But the point is to have not just negative things while you're wringing your hands if you don't want to do anything ... some vision of what you'd like to achieve. I think some view that at least parts of it can be achieved, possibly by alterations of Our second scenario looked very plausible to me and completely consistent with the privacy concerns that ... the DEAS, so that there seemed to be stats there that could be taken. Indeed, most of the things came up as issues as we discussed.

Paul Egerman – Software Entrepreneur

This is helpful. I really appreciate Bill Stead's comments, but I'm getting the sense, and maybe I've got this wrong, ... with it, those are the two points we want to make in our concluding paragraph. Is that correct? If we do that, we reference the learning health system and we say there are major concerns in this area we can do an aggressive schedule as long as we have large-scale operational environments where we respond to those concerns.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I have one to add. But you may, upon reflection, decide it's too detailed. But I hark back to the discussion we had with Farzad earlier today about the likelihood that some of the standards implied to operate. To have a UEL and a DEAS are interlocking with standards that are necessary for other efforts that are going on and suggest that some early pilots or some early demos or something could identify what I'm calling the sweet center of the required standards.

Paul Egerman – Software Entrepreneur

I like the concept. I'm just not sure it belongs in a concluding paragraph.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I'll let you decide.

Paul Eggerman – Software Entrepreneur

Here's the way I like to think about a concluding paragraph. The "P" stands for president. This is the one paragraph that if you had ten seconds with President Obama you'd want him to hear. That's the way I'd like us to think about it.

Carl Gunter – University of Illinois – Professor

I thought that the idea ... there are really good points.

Paul Eggerman – Software Entrepreneur

Pardon me?

Carl Gunter – University of Illinois – Professor

I thought ... three points. My first point is there's some really good upside here and it's worth trying. The second thing is there is some feasibility and policy problems that will not make this an obvious way to proceed and it's going to be obvious. A third point is that despite being obvious we can make progress in an aggressive way with effort. So those are the three points that you would say to Obama.

Paul Eggerman – Software Entrepreneur

What do people think?

Richard Platt – Harvard Medical School – Professor & Chair

It sounds good to me. Can we ... some of the major problems that we see? Rather than simply say we've identified some problems, I think it would be worthwhile to name the most important ones that we see so that they're right there for the president.

Carl Gunter – University of Illinois – Professor

The toughest one, I thought, was this one that Wes and Dixie both referred to is what I would describe as a trust management problem or a trust negotiation problem, which is if you take the DEAS and it asks a question. But it's hard to say who goes first in terms of how the answer occurs, how do I make the index to determine what the answer ought to have access to? That's a tricky thing and it has a lot of mixture of policy and technology in it and it's outside of what we've been able to do technologically. That seemed like the hardest thing to do in

M

I think several of us might have our own hardest thing. I'm not sure we need to make that list during this call. But I'd just like to, maybe in our correspondence we can nominate some things and then, Paul, you can decide how to weave in the ones that are most deserving of—

Carl Gunter – University of Illinois – Professor

I'd be curious to hear some of the others from other people, though.

Stan Huff – Intermountain Healthcare – Chief Medical Informatics Officer

The thing that I've been puzzling on is, or that's of concern is, I think we mentioned earlier just sort of the complexity. You all focused on great issues around security and the part that I'm closest to is actually creating semantic meaning that would allow somebody to ask the DEAS for something and reliably get back what they were expecting, and knowing the structure and the semantics of that information. I think that's clearly doable, but the set of definitions, if you will, and the common understanding of how we understand the structure and the semantics of the information that's being exchanged isn't discussed anywhere or to the level that I think people would understand the kind of effort it's going to take to do it.

I think it's clearly doable. I think it's highly desirable. But I think people are assuming that it's sort of as easy as saying I'm going to use XML and it's done. Choosing XML or some other framework in which you define your semantics is like the first step on a 1,000-step journey of defining what blood pressures and heart rates and substructures related to the context of the acquisition of that information. Somehow, if I were to say the thing that I'm most concerned about is not that that's not solvable, it's just that when

we start working on it we need to anticipate the complexity and the amount of work that is to come to common agreements about the semantics of the information we're exchanging.

Paul Egerman – Software Entrepreneur

Okay.

Richard Platt – Harvard Medical School – Professor & Chair

I would nominate the population health issues generally as a set of tasks that will lead to the addressed—

Paul Egerman – Software Entrepreneur

As we're going through this let me just make the observation that we did already, Section C, list what we consider to be the top three policy issues. What we listed there were privacy, population health, although we called it multi-patient, multi-entity analysis or something like that. Then we just said governance, which was a catchall for the DS, but also how this all is going to work. I don't know if that's the list of the top three or not, though.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

I think the top of the list is operational feasibility.

M

I think we're going to cycle on this.

Paul Egerman – Software Entrepreneur

Yes, I think so too.

M

I do want to make a point related to the comment that Stan made, which has got a lot to do with your interpretation of the report. But my belief is that the authors of the report envisioned that semantic reconciliation that he's talking about as being a capability of the DEAS and not something that is solved in a framework of semantic standards associated with the DEAS that everybody conforms to.

Paul Egerman – Software Entrepreneur

It's funny, when I heard Stan make the comments about semantic interpretation, in my mind I filtered over to what Dixie just said, a variation of it, which is, how does this thing really work? That's what I heard. Maybe I didn't hear Stan correctly.

M

Here's a way to put the question. Is it mandatory, remember there are multiple DEAS', there's not a single ..., is it mandatory that there be detailed semantic standards such that all information offered to any DEAS it is offered to can be interpreted the same way by anybody that understands those semantic standards.

Paul Egerman – Software Entrepreneur

My answer to that is that's a great question, but it seems like that's too detailed for our concluding paragraph.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

Can I offer something I wrote down during the hearing that I thought was, I totally agree with Stan. John Madison, at our hearing, said the following, which I think is just right to the point, he said, our existing semantic constructs focus on patient care. The PCAST approach provides value for secondary purposes at the expense of the expressivity. I think he was right on target. All of our semantics—

Paul Egerman – Software Entrepreneur

Richard Platt says it does not do that. He says it doesn't work for secondary use. I don't mean to put words in your mouth, Rich, but that's what I'm hearing.

Richard Platt – Harvard Medical School – Professor & Chair

Yes.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

But he was saying the way it's being proposed, you know, breaking it down to the data element level. It's a fine level of granularity. You lose that whole context that's essential for patient care but may not be essential when you're a researcher out there looking for a cohort.

Paul Eggerman – Software Entrepreneur

We made that observation already in Section C. Rich and I have been working on some revised wording that you haven't seen yet, but we are going to be making that observation in Section C.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

If a president's going to read it, I think it's got to be made in a way that the layperson can understand. The semantic issue is huge.

Paul Eggerman – Software Entrepreneur

I understand. Also, don't get me wrong, I'm not making any commitment that the president will read it, that is more like a metaphor, but he might. I'm trying to understand, so we have this concept of, people want to talk about the top two or three things that they have concerns about, but the sense I had is also perhaps we're going to do that through some e-mail trail in terms of trying to get people to write that down. But once we start doing that we head down a certain path and it seems like there's a lot of issues. Are you trying to say something, Bill?

William Stead – Vanderbilt – Chief Strategy and Information Officer

Yes. I think this is an insolvable direction, and that's really why I advocated what I said. We worked very hard in making many very important points through the report and linking them together. Everybody has the things they're most interested in. If we try to put all of them in a concluding paragraph, we're licked. I think the concluding paragraph needs to be at a very high level and actually have the summative message, not a collection of people's highest concerns.

Paul Eggerman – Software Entrepreneur

I agree.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Can I ask a question about the high-level issue? If someone were to read the bullets that we've described and then let's say someone else in the president's office looked only at the last paragraph and then had to give a 10 second summary of it in a report on 20 things to the paragraph, what would his ten second summary be? I think it would be they're against it.

William Stead – Vanderbilt – Chief Strategy and Information Officer

You think it would be what?

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

They're against it.

Paul Eggerman – Software Entrepreneur

I don't know, but the way I look at this, Wes, is this our report, we should say in it as best as we can what we think is the right thing to say that will be giving guidance to ONC. I like the three things, so they might sequence it a little bit differently, but I really don't care about the sequence, the three things being that there are major concerns. We can put some words about what the concerns are, but I agree with what Bill was just talking about, at a high level.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

I agree with that.

Paul Egerman – Software Entrepreneur

Let me finish, Wes. The second thing is that there is a way to do an aggressive schedule, that it requires significant operational experience. The third thing, I know Carl put this first, is there's a compelling vision here. The reason why I want to put it third is somehow the concluding paragraph has got to be something like ONC has an interesting challenge of somehow balancing this aspirational goal or this compelling vision with practical realities.

Dixie Baker – Science Applications Intl. Corp. – CTO, Health & Life Sciences

That fits. I like that.

Paul Egerman – Software Entrepreneur

So that to me the intent of the summation is to summarize our whole report, and so if Dixie says she likes it, maybe I should stop talking and declare victory.

Carl Gunter – University of Illinois – Professor

Yes, I like it too.

Tim Elwell – Misys Open Source Solutions – Vice President

I do too.

Stan Huff – Intermountain Healthcare – Chief Medical Informatics Officer

I like it also.

Wes Rishel – Gartner, Inc. – Vice President & Distinguished Analyst

Me too.

Paul Egerman – Software Entrepreneur

Okay, so we've got a good conclusion. Now, the challenge we're going to have as a group is also to make sure that we have an entire report that everybody is comfortable with. But I think we're 95% of the way there. Maybe we've got some work on this middle-out thing, there's a fair amount. We've given some assignments to some people on some things that we're going to be running, so we'll be turning out another draft hopefully over the weekend or maybe Monday or Tuesday for everyone to look at.

What I'm going to ask you to do is go through it again one more time and feel free to continue, we'll wordsmith it if we need to yet again to try to make sure that we have consensus. I want to do this mainly over e-mail. The only caution I want to give people is to make sure that we don't lose the forest for the trees here. I think Bill Stead's comments were really very good. We can't view this final report as our last gasp effort to make one more observation, one more thought about the report because there will always be one more to be said about something like this. What we said in the conclusion is very valuable. What we said in the report itself in Sections C and D is extremely valuable. I think at ONC we're saying here are the steps you can take, here's what's feasible, and here are the issues. I think this workgroup has done a terrific job with an unbelievably difficult challenge. Those are my concluding comments. Do you have anything you want to say, Bill, or that anybody else would like to say?

M

I just want to thank you, Paul, and Bill and the others. This has been a lot of work and I think we've done it in a very nice consensus process. I have to agree with you, it's clearly not the last statement on this. It's just hopefully a constructive additional statement.

William Stead – Vanderbilt – Chief Strategy and Information Officer

I think we're in a good place.

Paul Egerman – Software Entrepreneur

Would anybody else like to say anything? In some sense, it's our very last meeting. It will be like we should have a little song or something.

Carl Gunter – University of Illinois – Professor

... party. I also greatly enjoyed and learned a lot from the discussions. I really appreciate

Paul Egerman – Software Entrepreneur

I agree. I learned a ton from absolutely everybody. I want to give a special thanks to Bill Stead. You were terrific. You were very patient at training me, so I want to say thank you to you. I also want to take a minute to thank all the ONC people, who may be on the line still. I don't know if they're still on the line. Farzad has been terrific, Doug Fridsma, Jodi Daniel, and Jamie Skipper. Judy Sparrow is in a league of her own in terms of putting together all of these things and doing a terrific job, especially since some of us know this is the second one of these that she had to do today, so it's already been a long day for her. I want to say thank you, and unless somebody else has another comment, let's open the lines for public comment.

Judy Sparrow – Office of the National Coordinator – Executive Director

Thank you, Paul, and thank you, everybody; a terrifically collegial group. Operator, can you see if there's any public comment, please?

Operator

We do not have any comments at this time.

Judy Sparrow – Office of the National Coordinator – Executive Director

Thank you, operator. Thank you, everybody.

Paul Egerman – Software Entrepreneur

Thank you very much.